



Update from CDC: Public health's response to early onset breast cancer

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Advisory Committee on Breast Cancer in Young Women (ACBCYW)

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U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Background

- Breast cancer is the most commonly diagnosed cancer among women
- About 10% of invasive breast cancer cases occur among women younger than age 45.
- These women often face difficult medical, psychosocial, financial, and health issues related to their diagnosis and treatment for breast cancer.
- Nearly 30% of women diagnosed with early breast cancer develop metastatic breast cancer (mBC) with an expected median survival between two to four years.



The Legislation



The Breast Cancer **Education and Awareness Requires Learning Young Act (EARLY Act)**: the first piece of legislation related to breast cancer in young women, enacted in 2010. The EARLY Act authorizes CDC to:

Develop initiatives to **increase awareness of breast health and breast cancer risk among young women.**

Establish a Federal **Advisory Committee on Breast Cancer in Young Women (ACBCYW).**

Establish **applied public health research program** about breast cancer in young women

Establish a **program to provide support to young women living with breast cancer**

Grantees and Programs

*Partnering to support young women
at risk for or living with breast cancer*

Programmatic Support

CDC currently funds 7 grantees through the *Multiple Approaches to Increase Awareness and Support among Young Women Diagnosed with Breast Cancer* five year cooperative agreement (2014-2019).



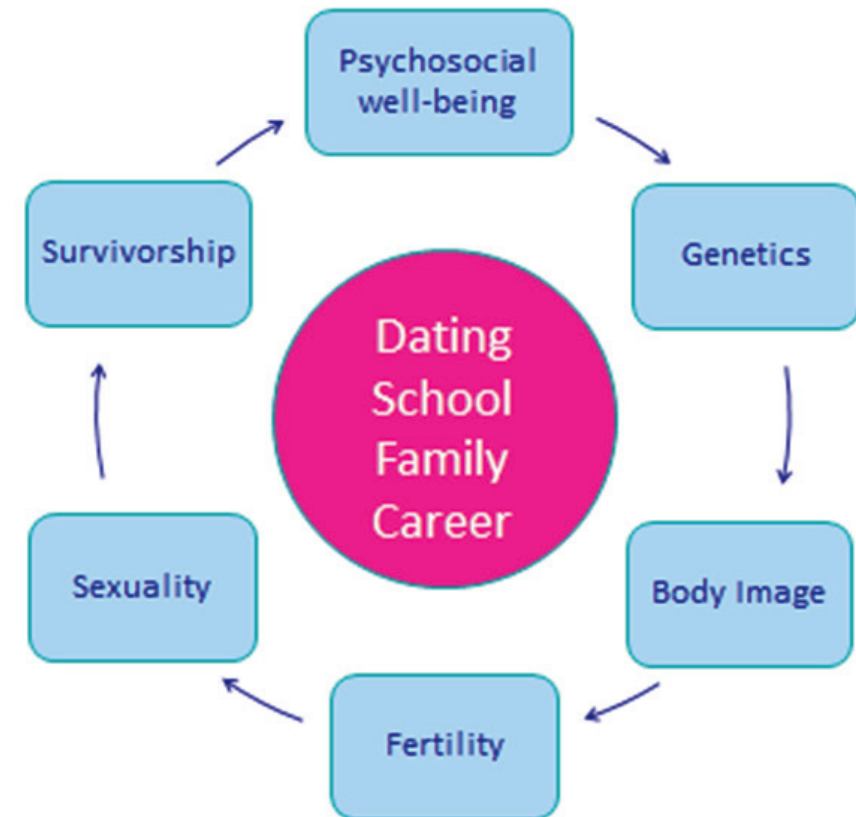
JOHNS HOPKINS
UNIVERSITY



Johns Hopkins Medical *Young Women's Breast Cancer Program*

- Enhancing delivery of care and wellness first visit through continuum of care
 - One-on-one patient navigation: 425 young women/year
 - Multiple psycho-educational peer support groups for early stage and metastatic young women
 - On-line nutrition course with accompanying recipe booklet: 200 participants
 - Access to fitness and wellness with gym partnerships and online programming that reduces barriers to exercise

Figure 1: Experiences of YBCS



Johns Hopkins Medical *Young Women's Breast Cancer Program*

2018 -2019 DP-1408 Successes

A multi-disciplinary program that meets the unique medical, emotional and practical needs of young women living with and surviving breast cancer.

Education for patients, survivors and providers through print materials, in-person events and technology

- Binder for young women: 150-200 distributed/year
- 3 Webinars with global reach (600 real-time participants; 1200 archived webinar views)
- 70 website videos with distinct topics in our library; viewed 600 x/mo
- Mobile App for patients: tools for scheduling, education, navigation, and treatment

Sharsheret

Thriving Again Survivorship Program

- During the 2018-2019 grant year:
 - Disseminated 154 updated *Thriving Again* wellness kits to YBCS
 - Presented BRCA genetics webinar for 400+ participants, featuring updated information on new recommendations in genetic testing.
 - Implemented online, patient navigation resources for YBCS and caregivers.
 - Conducted 2 peer support and story sharing training webinars for 112 YBCS
 - Established partner network of 90 agencies providing YBCS support in local communities.



FORCE XRAYS Program

- During the 2018-2019 grant year:
 - FORCE's eXamining the Relevance of Articles for Young Survivors (XRAYS) program, helps young breast cancer survivors and high-risk women to better understand breast cancer research and news that is relevant to them.
 - XRAYS allows users to submit articles for review and subscribe to an XRAYS quarterly digest.
 - XRAYS Metrics:
 - **38** XRAYS article reviews published.
 - **10** blog posts about the XRAYS program
 - Reached **140,000** readers

XRAYS

Cancer-related news is often misleading and hyped. Launched in the Fall of 2015, our eXamining the Relevance of Articles for Young Survivors (XRAYS) program translates breast cancer research into language that is clear and accessible to help guide the breast cancer community through the media clutter.

“There is so much toxic disinformation in the world of hereditary cancer. FORCE’s XRAYS series is an antidote.”

- Judy Wu, My 2¢ op/ed

In 2018, our team reviewed, simplified, and rated media for accuracy and relevance and published 38 reviews. We shared 10 blog posts related to XRAYS reviews and presented the XRAYS program at medical and scientific meetings nationwide. On November 27, 2018, we published our 150th review - helping 140,000 readers evaluate the accuracy of media coverage and the relevance of research to their situation. It's all about help, not hype!

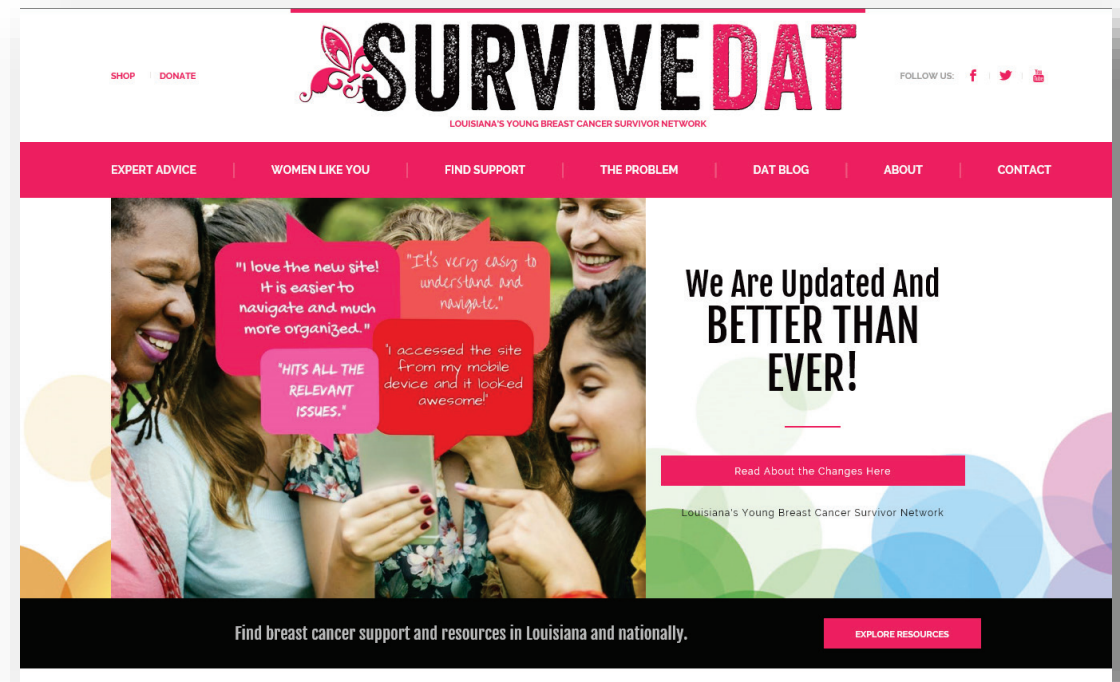
LOW XRAYS MEDIUM XRAYS MEDIUM-HIGH XRAYS HIGH XRAYS

“Finding out that I carried a BRCA2 genetic mutation was a very frightening experience that made me feel very vulnerable. In my quest to find information about what this meant to me, I was astounded by the sheer volume of confusing information in the media. The XRAYS program summarizes this info into easily accessible articles that put my mind at rest.”

- Caroline Presho

Gulf States Young Breast Cancer Survivor Network (GSYBCSN)

- An online health resource for young breast cancer survivors (YBCS) living in Louisiana, Alabama, and Mississippi.
 - Digital platforms:
 - SurviveDAT in Louisiana;
 - SurviveAL in Alabama;
 - SurviveMISS in Mississippi.
- Purpose of the GSYBCSN is to increase the availability of and access to services and support for YBCS including those with metastatic cancer, and their caregivers and families in the gulf states region



Gulf States Young Breast Cancer Survivor Network (GSYBCSN)

During the 2018-2019 grant year:

- Developed a video-based psycho-social support series with a board certified oncology counselor, which will be rolled out over the next 5 months.
- Disseminated educational information to 852 physicians across the three states to update them on concerns important to YBCS.
- Developed and leveraged a new partnerships:
 - Collaboration with Komen affiliates on a metastatic Breast Cancer Conferences in Louisiana and Mississippi.
 - Participated in Alabama's annual Women's Cancer Survivor's Workshop
 - Young Survival Coalition's Annual Summit for YBCS, as well as FORCE's annual conference

BY: BAILEY ANN HENDRICKS, RN, BSN, CO-SURVIVOR
06/01/2019

Understanding Financial Toxicity And How To Deal With It

Did you know that cancer is one of the most expensive illnesses to treat in the United States? It is no wonder that cancer patients are more likely to experience financial toxicity. Financial toxicity describes the problems related to the cost of treatment. Specifically, how out-of-pocket costs can cause financial problems for patients. Out-of-pocket costs can include copayments, deductibles, and coinsurance. These out-of-pocket costs can be from staying in the hospital, having procedures and tests done, doctor appointments, and/or prescription medications.

Categories
GENERAL

Recent Posts

- Understanding Financial Toxicity And How To Deal With It
MAY 01, 2019
- What I Wish I Knew: Lean In
APR 03, 2019
- Here To Help: Young Breast Cancer Survivor Organizations
MAR 05, 2019

Tags

ALL EARLY DETECTION
INFERTILITY
CERVICAL CANCER AWARENESS
BREAST CANCER FAMILY
PERSONAL LIFE SINGLE
SCREENING FINANCIAL IMPACT

Young Survival Coalition

- **Reach and Impact in 2018**

- 10,000 survivors supported
- 3627 co-survivors supported
- 285,000 visitors to youngsurvival.org
- 1900 educational Navigators ordered
- 100+ State Leader volunteers who serve young adults affected by breast cancer
- 170+ Face 2 Face in-person support groups across the U.S.

- **2019 YSC Summit**

- 507 attendees including 86 co-survivors and 67 YMBC
- 81% of attendees agreed or strongly agreed they learned something new
- 89% of attendees agreed or strongly agreed the co-survivor hangout enabled them to meet and form connections with fellow co-survivors
- 200+ registrations for Continuing Education livestream for healthcare providers



Dana Farber

Young and Strong Survivorship Program

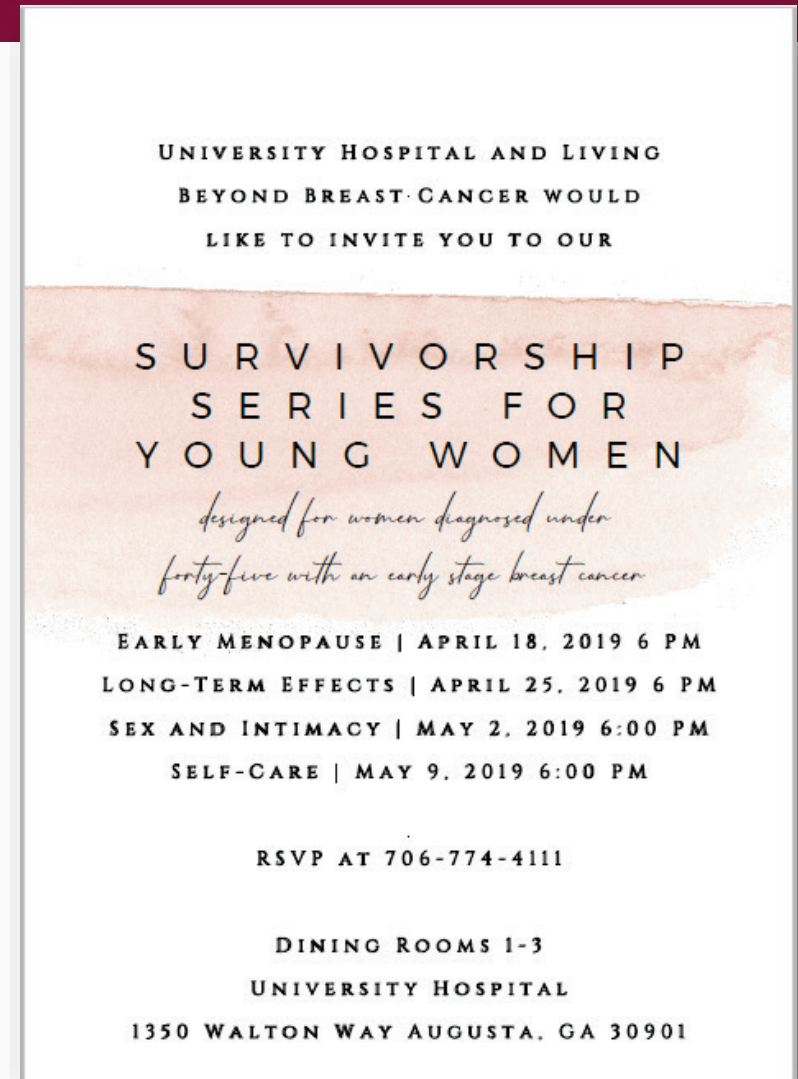
- Completed fall 2018 **Forum for Young Women with Breast Cancer**: 95 attendees
- 105 YBCS Navigated to Survivorship Visit
- 3 Phone Support Groups with YBCS
- 2 Sexual Health Workshops for Couples and YBCS
- 4 Webcasts on topics relevant to YBCS



SoulMates offers peer support for breast cancer patients.

Living Beyond Breast Cancer

- Implemented the *Survivorship Series for Young Women* to be delivered by trained professionals within cancer centers that serve *underserved* YBCS.
 - Collaboration with medical centers nationwide building on LBBC's extensive engagement with the medical community
 - 15 nurse navigators trained
 - 7 navigator led sessions have engaged 126 YBCS
 - **Anticipate up to 200 additional YBCS reached in 2019**
- Current program is being evaluated by CDC for utility and scalability



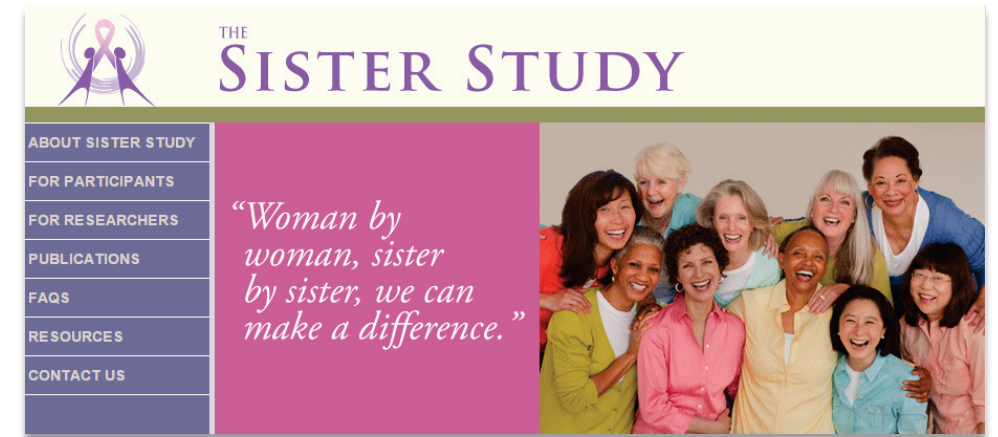
Applied Public Health Research

Economic impact of early onset breast cancer diagnosis

EA Activities: Research

Completed Activities

- ❑ Walking Together: Making a Path toward Healing
- ❑ Literature Review/SME Panel: Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course
- ❑ Estimating Infertility Among Breast Cancer Survivors
- ❑ Health Insurance Coverage of Genetics Services
- ❑ Economic Burden of Breast Cancer in Young Women Aged 15-44 Years in the United States, 2000-2010
- ❑ Economic Impact of Late Stage Breast Cancer Diagnosis and Benefits of Reducing Alcohol Consumption Among Women Aged 18-44 Years at High Risk for Breast Cancer
- ❑ Sisters Study and Two Sisters Study: national survey of young breast cancer survivors and their sisters



Economic Impact Studies


- **Study to assess the lifetime economic burden in younger, midlife, and older women with metastatic breast cancer**
 - Ongoing study estimating economic factors related to mBC: lost productivity, direct costs, years potential life lost, and cost of care per population;
 - Literature Review published in *Breast Cancer Research and Treatment* in January 2019
 - Additional findings anticipated in early 2020
- **Economic Wellbeing of Young Women with Breast Cancer: Insurance, Employment and Financial Experiences**

Health Care Provider Education

*Supporting Medical Education for PCPs Regarding Early
Onset Breast Cancer*

Project Overview

- Funded by CDC Cooperative Agreement OT18-1802
- Provider-focused branch of CDC's *Bring Your Brave* patient education campaign
- Goal is to develop innovative, evidence-based provider education materials on early onset breast cancer with input from stakeholders



Caring for Young Women Who Are at High Risk for **EARLY-ONSET BREAST CANCER**

ACOG is partnering with CDC to develop provider education tools for early-onset breast cancer


Available today: Summary of Screening, Counseling, and Testing Guidelines

- Who is at risk for early-onset breast cancer and what are the current screening guidelines?
- What are the best strategies to use to communicate with patients about early-onset breast cancer risk?
- What are the best risk reduction strategies for preventing early-onset breast cancer?
- What are the current genetic counseling & testing guidelines for early-onset breast cancer?
- What are the possible next steps after screening women at high risk for early-onset breast cancer?

Coming in 2020: FREE CME-accredited e-modules that aim to

- Improve awareness of early-onset breast cancer among medical providers
- Equip medical providers with the skills to identify and counsel young women at high risk for early-onset breast cancer
- Address the patient-provider communication gap

More Information
www.cdc.gov/BringYourBrave
Facebook: CDCBreastCancer | Twitter: @CDC_Cancer
(800) CDC-INFO (800-232-4636) | TTY: (888) 232-6349



***Bring Your Brave* - Campaign Metrics & Progress**

CDC-developed tools and outreach programs for young women and health care providers

Know:BRCA Clinical Decision Support Tool

Know:BRCA: an interactive online tool that estimates a woman's chance of having a BRCA gene mutation based on her personal and family history of breast and ovarian cancer.

- 2014-2018, more than **122,000 users** have visited the site, with **4,200 users/month** visiting the site in 2017
- **>77,000 views** of the Know:BRCA's Learn the Facts pages
- **4,072 women** have completed the **Know:BRCA assessment** and learned their risk for a BRCA gene mutation
- **581 providers** have downloaded a starter kit to explore using *Know:BRCA* in their practice
 - More than 15 starter kits downloaded each month on average



Bring Your Brave Campaign



Multi-media storytelling campaign targeting young women *and* health care providers, with an emphasis on young women at higher risk for early onset breast cancer (including HBOC).

Platforms and methods:

- Facebook, Twitter, YouTube, Tumblr, LinkedIn, & Instagram
- CDC website with resources for young women and health care providers
- Medscape - Continuing Medical Education (CME) training
- Paid Media

Bring Your Brave Campaign



The campaign objectives are to reach young women and:

Encourage

Them to learn their family history.

Educate

On the risk factors for breast cancer before age 45.

Inspire

Women to talk to their health care providers if they think they may be at a higher risk for breast cancer.

Incite

To live a healthy lifestyle and be aware of their own breast health.

Cumulative Results

In total, the *Bring Your Brave* campaign has generated:

- **114 million impressions across social media, blogs, search engines, digital display, and earned media;**
- **2.28 million video views;**
- **1.4 million social media engagements; and**
- **337,000+ visits to CDC's *Bring Your Brave* website.**

The campaign has also received a CDC Award for Excellence in Communication and a Certificate of Excellence: Public Service through the Public Relations Society of America.

Most importantly, campaign efforts have encouraged thousands of women to learn their family history of breast cancer and be aware of their own breast health.



Bring Your Brave Campaign

Health Care Provider Outreach

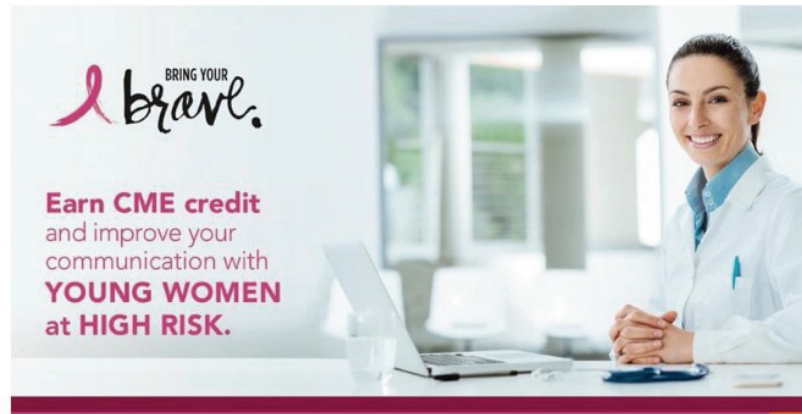


Centers for Disease Control and Prevention

113,175 followers

19 d

This National Cancer Control Month health care providers can take CDC's new CME course providing clinicians with a better awareness of the ...see more



60 Likes

CDC Initiated Health Care Provider component of the campaign in 2017

• **Formative Research:**

- CDC fielded a **DocStyles** survey of doctors regarding HBOC
- Literature review
- Medscape survey of internal user needs

• **CDC launched the Bring Your Brave Health Care Provider website with:**

- Risk assessment tools and screening guidelines
- Tailored, downloadable fact sheets
- Access to a CME training course

• **Launched Medscape CME training for HCPs and reviewed CME metrics.**

• **Developed Provider Education training videos in 2018**

Bring Your Brave

Health Care Provider Outreach

Since the Medscape CME launch in late January 2017, the *Bring Your Brave* health care provider CME has resulted in:

- **14,849 learners**
- **7,328 test-takers**
- **7,174 CME certificates** issued
- **10,738.75 CME credits**
- Positive feedback from those who completed the CME training



What's Next: Research and Results

Filling the Knowledge Gaps



Direct-to-Consumer Genetic Testing Awareness



Provider Education





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Health and Human Services**
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BRING YOUR
brave.